

Mark Your Calendar

Support Meetings

First Saturday
of the Month

When:

May 1, 2010 *

June 5, 2010

* There is a change of location
and time for the May 1
meeting - see back page!

Business Meeting

4:30 - 7 p.m.

Support Meeting

7 - 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

July 21-25, 2010

Internat'l Fragile X
Conference
Hyatt Regency
Dearborn

Register @ fragilex.org

August 21, 2010

FXAM Picnic & 5K
Clarkston, MI

Fragile X Association of
Michigan

Contact Information:
313-381-2834

fraxmich@hotmail.com

FXAM.org

Welcome to the D

Don your Tiger hat (or t-shirt) with our Old English D, snap a photo and send it to Mary Beth at mblangan@hotmail.com before you forget! If you don't own D wear, stop at the mall, try on a hat and snap a photo right there. The photos - of your child or children or the whole family - will be added to a collage at July's International Conference titled *Your Michigan Fragile X Family Welcomes you to the D!*



Three Cheers for...



Austin Nantais

Celebrated his 18th birthday in March like any typical male would love to... at Hooters!

Way to go Austin! We think his smile tells us he liked it.

Our Michigan Advocates!

Thank you for taking the time to be our voice in Washington!

Read Kim's recap of this year's journey on page 2.



FXAM Member Conference Scholarship

The Fragile X Association of Michigan (FXAM) funds a conference scholarship every two years to help our members attend the international Fragile X conference. This year is no different simply because it's in our home state! If you are a Michigan resident AND a FXAM member, you are eligible to apply for a scholarship. *Continued on page 2.*

From the Presidents Desk *by Laureen Majeske*

Three months and counting! **We are still in need of volunteers.** Can you help? If you can, please go to fragilex.org, click on the conference link and go to Volunteers. There you can sign up for any day, any time and even pick the area you would like to volunteer in. Ask your friends and relatives and make it a family affair! Our committees can also use more volunteers. Check out the different committees at fxam.org and contact the chairperson to help. Thanks!

Teacher scholarships are now available. These can be for your teacher, your para- and other support staff or professional that works with your child or family. You will find in this newsletter an application to apply. All registration

information must be filled out with the application. Your teacher/professional will be registered through FXAM and not through the National Fragile X Foundation. The deadline to apply is May 15, 2010. Applicants will be notified by June 1 if they have been awarded a scholarship and the amount awarded.

The conference agenda will be set so that the majority of sessions for educators will fall on one day. Normally it is on Thursday or Friday. That date has not yet been determined, so if they are applying for a one day registration, they can put down either Thursday or Friday. Once that day is set, we will notify all applicants and we can change their date

of attendance if they so choose.

These scholarships are available because of a generous donation from the Fragile X Resource Center of Missouri. The scholarship and registration form is an insert in this newsletter so you can easily share with others.

If you know of any business or organization that would like to become a sponsor, sponsorship details are also included as an insert, please pass it on. Sponsors also help fund our scholarship programs.

Also, check the newsletter for information on our FXAM member scholarships. **Register @ fragilex.org**

Hope to see you soon!

Advocacy Day 2010 - One Hundred for One Million *by Kim Young*

I have been very fortunate to have attended Advocacy Day every year since it's conception in 2004. This year, twelve people from Michigan were there to represent us from three generations of our fragile X families. It is an empowering experience that allows you, armed with stories of your personal experiences living with fragile X, to make a difference. This year was no exception, but in many ways was better than any year before. I decided to take both of my children with me this year, Andrew, 14, and Ally, 12. No other field trip or history lesson can compare.

Like years past, we went requesting federal funding through the Centers for Disease Control (CDC) and the National Institutes of Health (NIH). But the past two years, we have also gone requesting legislation, the ABLÉ Act (Achieving a Better Life Experience Act) and the Harmful Restraint and Seclusion Act.

Both of my children attended all of the meetings and I even put Ally on the spot in a few of them to have her voice heard. The day that we were all on The Hill, over one hundred people from over 35 states, the Harmful

Restraint and Seclusion Act was passed by the House of Representatives. I have to say, after hearing stories from our "fragile X family", from all over the country and even from our own backyard, of physical and emotional abuse at the hands of some in education entrusted to care for our kids, the little hairs on the back of my neck stood up. History was made!

Please consider attending next year. You need not be an expert on government or the science of fragile X. You need only be an expert as a mom, dad, grandparent or sibling living with someone with

FXAM Member Conference Scholarship *continued from page 1*

All applicants receive a percentage of the conference fund. Every member is eligible, it's not limited to one per family.

Write a short letter of application and send it to Laureen Majeske, FXAM president, at lmajeske1@comcast.net or 35746 Woodvilla Drive, Sterling Heights, MI 48312. In your letter of

application please include your name, address, phone number, email address, and if this is your first conference.

Your Email must be sent (or envelope postmarked) by **May 7, 2010**. You will be notified by May 22 as to the amount of funding you will receive. It will be given to you as a reimbursement after you submit receipts. Submission details will

be in the award letter.





Teacher/Professional Scholarship Application

Due Date: May 15, 2010

Name: _____

Title: _____

Address: _____

City, State, Zip: _____

Email: _____

Phone(s): _____

Name of school or learning facility: _____

Do you currently serve someone with FX? _____

Please indicate the type of registration for which you are applying:

- One day: _____ Entire conference

Have you attended a prior International FX Conference? _____ If yes, which year(s): _____

Are you planning on registering your children for childcare at the conference? Yes No

Are you planning on staying at the Hyatt Regency Dearborn during the conference? Yes No

What do you hope to learn by attending the conference? _____

Please submit your completed application and conference registration form by May 15 to:

Laureen Majeske
Fragile X Association of Michigan
P.O. Box 1414 Troy, MI 48099-1414
laureen.majeske@fxam.org Phone: 586-978-9079

***Luncheon and banquet tickets are not included for single-day registrants. **All registrants will receive a t-shirt, tote and agenda. **Free parking. **Educator tracks will be Thursday or Friday. Register for either for a single-day registration. We will notify you as to the educator track day when the agenda is set. Your registration can be modified if needed. **Wednesday's Behavior Seminar is from 1 - 5 p.m. and is only for professionals.*

Scholarships will be awarded by May 22, 2010. Approved applicants will be contacted in June with the amount of scholarship money awarded. Registration must be submitted to the Fragile X Association of Michigan at the same time as the scholarship request.



12th International
FRAGILE X Conference
 Hyatt Regency Dearborn
 Dearborn, Michigan
 July 21 - 25, 2010

Conference Registration Teacher/Professional

Please print clearly:
Name(s) to appear on badge (include title):

Organization: _____

Address: _____

City _____ State ____ Zip _____

Email (required): _____

Possible CME credits, you will be notified if available.

For those paying their own registration (NOT applying for a scholarship):

Registration fees may be paid by check (payable to the NFXF) or by credit card. Payment must be received in order for registration to be confirmed by email. Cancellation and refund requests (*in writing*) through **July 7** will be refunded by check, less a \$30 administrative fee. **After July 7 we regret that no refunds are possible.**

For those paying their own registration (NOT applying for a scholarship):

METHOD OF PAYMENT

_____ Check _____ Credit Card

Card Number _____

Expiration Date ___/___/___

Name as it appears on Card:

Authorized Signature

NFXF Federal Tax ID #84-0960471

QUESTIONS?

Laureen Majeske
 Fragile X Association of Michigan
 P.O. Box 1414 Troy, MI 48099-1414
 laureen.majeske@fxam.org Phone: 586-978-9079

FOR OFFICE USE ONLY

CC Approval _____

Reg Confirmed _____

ADVANCE REGISTRATION FEES 2/1 to 5/15/09

includes Fri. luncheon and Sat. banquet (except for single-day registrations)

NFXF Member Rates

- Individual \$385
- Family (2 parents) \$685
- Student \$235
- Single Day Thurs__ Fri__ Sat__ \$195
- Single Day Wed Behavior Seminar \$125

Non-Members

- Individual \$445
- Family (2 parents) \$745
- Student \$335
- Single Day Thurs__ Fri__ Sat__ \$225
- Single Day Wed Behavior Seminar \$125

ADDITIONAL EVENT TICKETS

Henry Ford Museum – Exhibits & Dinner

Thursday 7/22/10 6 – 9pm

____ # of Aduldtickets X \$ 75each \$ _____

____ # of Childtickets X \$ 25each \$ _____

Luncheon Friday 7/23/10:

____ #Adult X \$ 35each \$ _____

____ #Child X \$ 25each \$ _____

Banquet Dinner Saturday 7/24/10

____ #Adult X \$ 75each \$ _____

____ #Child X \$ 25each \$ _____

*Kosher meals may be ordered for an additional fee

____ # of Kosher meals X \$10each \$ _____

Total \$ _____

I/We prefer our meals to be vegetarian.

Conference T-shirt (No charge; 1 per registrant)) Please indicate size preference:

- Medium
- Large
- X-Large
- XX-Large

12th International Fragile X Conference, July 21-25

Sponsorship Opportunities

The National Fragile X Foundation's Biennial International Conference provides corporate partners with the opportunity to be recognized for their contributions to and support of the Fragile X community. When you sponsor the National Fragile X Foundation (NFXF), you are partnering with an organization that is recognized worldwide for the programs, services and support it provides to the approximately 1 million individuals impacted by or at risk of developing a Fragile X-associated disorder.

The 2010 International Fragile X Conference gives Corporate Sponsors the opportunity to demonstrate their philanthropic efforts to an enthusiastic audience of parents, researchers and treatment professionals. Since the NFXF was founded the biennial conferences have been dedicated specifically to presenting a comprehensive perspective on all topics that affect the Fragile X community: scientific progress, medical advancements, emotional support, legislative activities, current and upcoming clinical trials, and up-to-date education, treatment and adult issues.

Attendance at this unique event is made up of individuals living with a Fragile X-associated disorder, family members, scientists, researchers and physicians, health care professionals, service providers, government officials, leaders from related industries, educators, and other stakeholders interested in the progress being made in the Fragile X field.

Sponsorship of the NFXF 2010 International Fragile X Conference connects organizations directly with leaders of the Fragile X community and signifies a strong commitment by the organization to improving the lives of individuals living with Fragile X and their families.

Luxury Sponsor \$25,000

- Keynote Speaker Opportunity* at NFXF International Conference Banquet & Opening Plenary Session
- One corporate-sponsored symposium* during time of choice for sponsor during the International Conference
- Maximum exhibit space allowed for private sector exhibitors (*and 6 exhibitor passes*)
- VIP seating and recognition at the Conference Banquet Dinner event and guest passes for 12 (*One full table*)
- Prominent recognition throughout the International Conference
- Full-page ad in the International Conference Agenda (*provided to each conference attendee & faculty*)
- Full-page ad in Conference Banquet program
- Conference Registrations for 6 individuals
- Corporate logo placement on Conference t-shirts and tote bags
- Corporate name and logo featured on the NFXF Conference webpage
- Recognition in the International Conference registration announcement (*sent to over 8,000 individuals in over 23 countries*)

Application form available at:

www.fxam.org/uploads/Corporate_Sponsorship_Application.pdf

Sponsorship Opportunities *(continued from page 5)*

Classic Sponsor \$15,000

- One corporate-sponsored symposium* during premiere time slot at the International Conference
- Maximum exhibit space allowed for private sector exhibitors *(and 4 exhibitor passes)*
- VIP seating and recognition at the Conference Banquet Dinner event and guest passes for 8
- Prominent recognition throughout the International Conference
- Half-page ad in the International Conference agenda *(provided to each conference attendee & faculty)*
- Full-page ad in Conference Banquet program
- Conference Registrations for 4 individuals
- Corporate logo placement on conference t-shirts and tote bags
- Corporate name and logo featured on the NFXF conference webpage
- Recognition in the International Conference registration announcement (sent to over 8,000 individuals in over 23 countries)
- **Available only to Members of the Corporate Advisory Council*

Hot Rod Sponsor \$10,000

- Maximum exhibit space allowed for private sector exhibitors *(and 4 exhibitor passes)*
- VIP seating and recognition at the Conference Banquet Dinner event and guest passes for 4
- Prominent recognition throughout the International Conference
- Half-page ad in the International Conference Agenda *(provided to each conference attendee & faculty)*
- Full-page ad in Conference Banquet program
- Conference Registrations for 2 individuals
- Corporate logo placement on Conference t-shirts and tote bags
- Corporate name and logo featured on the NFXF Conference webpage
- Recognition in the International Conference registration announcement (sent to over 8,000 individuals in over 23 countries)

Crossover Sponsor \$5,000

- One private sector exhibitor space *(and 2 exhibitor passes)*
- Half-page ad in the International Conference Agenda *(provided to each conference attendee & faculty)*
- Full-page ad in Conference Banquet program
- Conference Registration for 2 individuals
- Corporate logo placement on conference t-shirts
- Corporate name and logo featured on the NFXF International Conference webpage
- Recognition in the International Conference registration announcement (sent to over 8,000 individuals in over 23 countries)

Hybrid Sponsor \$2,500

- Half-page ad in the International Conference Agenda *(provided to each conference attendee & faculty)*
- Half-page ad in Conference Banquet program
- Corporate logo placement on conference t-shirts
- Corporate name and logo featured on the NFXF International Conference webpage
- Recognition in the International Conference registration announcement (sent to over 8,000 individuals in over 23 countries)

Roadster Sponsor \$1,000

- Half-page ad in Conference Banquet program
- Corporate name and logo featured on the NFXF International Conference webpage
- Recognition in the International Conference registration announcement *(sent to over 8,000 individuals in over 23 countries)*

Application form available at:

www.fxam.org/uploads/Corporate_Sponsorship_Application.pdf

Research Opportunity in Michigan



EMORY
UNIVERSITY
SCHOOL OF
MEDICINE

Department of Human Genetics

Fragile X Studies

Emory Study of Child Learning

The **Emory Study of Child Learning** is a new study being conducted in the Department of Human Genetics, Emory University, Atlanta, Georgia. Emory University has one of the longest-standing fragile X syndrome research programs in the world, led by Drs. Stephanie Sherman and Stephen Warren. Both are internationally recognized for their contributions to the field of fragile X research.

The purpose of this study is to determine whether children with the premutation have different learning skills or behaviors than children without the premutation. **Children between the ages of 6 years and 17 years who do not have fragile X syndrome are eligible to take part.**

The study involves four parts:

1. Completion of mailed-out medical and psychological questionnaires by one parent, estimated time 1 hour.
2. Saliva sample collection from child for DNA.
3. Participation in psychometric testing, estimated time 3 hours (Saturdays or Sundays).
4. Blood sample from child for FMR1 protein level testing (optional).

We are able to travel to the homes of families willing to participate. **However, we will also offer testing sessions at the International Fragile X Conference in Detroit this summer. To help with scheduling, we encourage interested parents to contact us in advance to discuss participation.** Compensation in the form of a \$25 gift card will be provided for each child who participates in the psychometric testing. An additional \$10 gift card is provided to each child who provides a blood sample.

All test results will remain confidential. A summary report of each child's psychological testing will be provided to parents.

If you know of someone who might be interested in participating in this study or if you would like additional information, please contact Krista Charen at (404) 778-8479 or kcharen@genetics.emory.edu; or Dr Gudrun Aubertin at (404) 778-8473 or gaubert@emory.edu.

What's new in Research:

Clinical Trials have started at Rush University (Chicago) and Emory University (Atlanta) for a drug that may reverse Fragile X symptoms and improve cognitive ability, U.C. Davis (Sacramento), Vanderbilt (Tennessee) and Indiana (Indianapolis) haven't started recruiting yet. This is only one med, from Hoffmann-La Roche, there are other drugs in trials from Novartis and Seaside Therapeutics as well. Stay current at Clinicaltrials.gov.

New Test: A newly developed test for Fragile X has proven to be accurate, time efficient and cost effective in diagnosing fragile X. The test could be used to identify newborns from a simple blood spot. The new test "overcomes the technical block to institute programs of newborn screening or population-based carrier detection for fragile X syndrome," according to the study, led by Feras M. Hantash, M.S., Ph.D., of Quest Diagnostics. At this time, until this test is released the FMR1 DNA test is still the standard,

New Genetic Test for Autism: A new genetic test for autism, known as chromosomal microarray analysis (CMA), finds more genetic abnormalities than two older tests, a study shows. It should be used **in addition** to the FX test (FMR1 DNA), it cannot be used to diagnose Fragile X, but is great at identifying FMR1 deletions.

e tra, e tra

Editors:

Mary Beth Langan

313-881-3340

mblangan@hotmail.com

Sally Nantais

734-282-7910

sallyn423@wyan.org

This newsletter is published quarterly and sent to all members and supporters of FXAM. Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

Newsletters are available on the web at FXAM.org

Would you like to be on our E-mail list? Send your E-mail address to Mary Beth or Sally.

May 1, 2010 Meeting Change!

Business Meeting, 4 p.m.

Liberati Home, 9068 Quandt St, Allen Park, 48101

313-381-2834

Support Meeting, Hyatt Regency Dearborn, 6:30 p.m.

Meet in lobby to be included in a FXAM photo to be featured in the NFXF Quarterly. Support meeting will follow in the Thomas Board Room, 2nd Floor (take a left off the elevator, first room on right.)

Pound the Pavement for Fragile X Auction/Raffle Items Needed

Any questions, please contact Peggy Branch at

peggybranch@comcast.net

248-647-4010

Welcome to the D



P.O. Box 1414

Troy, MI 48099-1414